

Section 23:

Estate Planning

Estate Planning is meant to serve as a plan to assist in the transfer of property, finances, and in some cases tax planning at the time of an individual's death. Estate Planning may require an individual to connect with a variety of professionals to address each service need, including an accountant, attorney, banker, financial planner, life insurance advisor, etc. For those in the disability community, some portions of estate planning will be necessary to set up prior to end stages of life for the individual diagnosed with the disability and their caregiver(s). Regardless of the age or health of the caregiver or individual, it is recommended to have your estate in place as an additional safety measure.

This guide is intended for general information only and is not intended, nor should it be construed or relied on, as legal advice. You should seek the appropriate counsel prior to making any decision and should contact an attorney if seeking legal advice.

Adult Support

When an individual reaches the age of 18, they are considered an adult. At that time, individuals can enter contracts, make their own medical decisions, manage personal finances, enter relationships or marriage, etc. If the individual or an adult in their life believes additional supports are needed because the individual is unable to manage their needs or communicate them, there are multiple options to help support them (i.e., Payee, Conservatorship, Guardianship, etc.).

If it is decided to remove decision making from an individual, certain facts and parameters must be met for those rights to be relinquished to another adult. The decision cannot be solely based on a specific diagnosis or medical condition. These parameters could include functional limitations (i.e., financial decisions, mobility, independent living, etc.) and if the individual's limitation will be continuing indefinitely. This may be done through the court system and can range in restrictions from a designated payee to guardianship.

It is recommended to contact legal counsel six months prior to an individual's 18th birthday if seeking additional support after they reach adulthood. When meeting with an attorney, they will provide their recommendation and walk you through the process to file the necessary paperwork.

If over time an individual has reached the ability to make independent decisions, restrictions can be terminated.

Conservatorship & Guardianship

The Iowa Developmental Disabilities Council publication on Guardianship:

<https://www.iowaddcouncil.org/guardianship-and-conservatorship-in-iowa>

Office of the Public Guardian:

<https://iowaaging.gov/elder-justice-adult-protective-services/office-public-guardian>

Conservatorship and Guardianship are two of the most common items discussed when an individual reaches the age of 18. A brief description of both is provided below.

Conservatorship is a legally binding document through the court system giving a responsible adult, known as a conservator, the authority to manage an individual's financial affairs (property and personal assets) on behalf of the individual "ward". To seek conservatorship, the conservator must prove the ward is unable to make decisions with clear and convincing evidence. Conservatorship requires extensive work to maintain and account for all the ward's funds. If an individual is under a conservatorship, it means the individual is not able to care for themselves. Conservatorship is not permanent, and a decision can be made through the court to relinquish.

Guardianship is a legal document through the court system giving a responsible adult known as a guardian(s) the authority to manage personal and/or finances of an individual. The individual may be an adult diagnosed with a disability. The courts will try to limit guardianship to the specific areas the individual needs assistance with and will have the final decision on the guardian based on the best interest of the individual.

Limited guardianship means the appointed guardian(s) can only make decisions specifically stated in the court order. A plenary guardian can make all decisions (medical, financial, and personal). In plenary guardianship there is guardianship of the estate and guardianship of the person. Guardianship of the estate focuses on the legal and financial affairs of the individual. Guardianship of the person focuses on health care and personal affairs of the individual.

Guardianship should always be considered the last resort. If an individual is under guardianship, they still have a set of rights by law. These rights include participating in decisions about their life, having personal privacy, having and/or maintaining personal relationships, the right to vote, etc. Guardianship is not permanent, and a decision can be made through the court to relinquish it.

Guardianship may not be an option for families due to several factors; the guardianship is too restrictive, the individual does not want to be placed under guardianship, the courts deny guardianship, or the option is too costly for some families, and they do not have the capability to cover the amount needed. With any of these options, it is recommended to look at alternatives to ensure the individual is protected, while still maintaining their desired level of independence.

Alternatives to Conservatorship & Guardianship

If conservatorship or guardianship is not necessary, the below list of alternatives is available to support an individual and allows them to maintain a level of independence.

Advanced Treatment or Advanced Healthcare Directives is a vital part of supporting an individual when a more restrictive guardianship is not needed. Having Advanced Treatment Directives in place prior to a medical emergency ensures if a situation arises, the patient will receive their desired level of care. Living Wills and Medical Power of Attorney make up the advanced treatment directives or advanced healthcare directives.

- **Living Wills** provides written documentation for specific medical treatments, medications, and procedures you wish to receive or refuse if you are incapacitated and unable to make the decision for yourself. Unlike a Power of Attorney there is not a set individual (agent) making decisions on your medical care in the moment. The document is a set plan you have created for your healthcare team to make medical decisions when you are incapacitated. It is recommended to have a Medical Power of Attorney to help resolve any disagreements on the decisions in your Living Will. Decisions include cardiopulmonary resuscitation, artificial nutrition and/or fluids provided to you, brain activity, body disposition, etc. By completing your advanced directive now, you know your wishes are being met if you reach the point of being unable to make decisions for yourself. The Living Will only applies to medical situations and has no bearing on financial decisions. You can make changes to your living will at any time.
- **Iowa Physicians Order for Scope of Treatment (iPost)** is a form listing the wishes of an individual in need of life sustaining care. This is a recommended form if a living will has not been created. Medical staff utilize the form to maintain the wishes of the patient in the event the patient is unable to express their desires. Items listed on the iPost include administration of cardiopulmonary resuscitation (i.e. – what happens in circumstances where the patient has no pulse and is not breathing), level of medical interventions in the event of a medical emergency (i.e. – comfort measures only, limited interventions, or

full treatment), use of medically administered nutrition by tube (i.e. - artificially administer nutrients for patients who cannot take oral nutrition or hydration by mouth), and the rationale for the orders.

- **Medical Power of Attorney** information is listed in alphabetical order in this section under Power of Attorney.

Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law protecting sensitive patient health information. A patient's information cannot be released without consent or knowledge. An individual has the option of signing HIPAA releases to allow people they trust to access their medical records (i.e., an independent adult can sign a HIPAA release allowing their parent to have access to their medical records from the doctor's office to ensure they maintain proper health).

Microboard is a small, nonprofit group of people serving one person who has a disability. The board makes sure the person has all the necessary support and services. Support can be unpaid "natural" support from family and friends, or paid staff can be hired to provide support. Widespread use of the microboard model began in Canada with the Vela Microboard Association. Today, there are several state microboard groups and many single microboards throughout the United States. <https://velacanada.org/resources/microboards>

Power of Attorney (POA) is a legal document allowing an individual (principal) to choose someone (agent) who manages their financial, medical and/or property affairs. There are 4 general POA's and what the agent can and cannot do is based on the specific POA. In some cases, the agent will only manage the affairs if the principal is rendered incapacitated or only approved to act on behalf of the principal in a limited timeframe. POA can be permanent or temporary and can go into effect immediately or after the occurrence of an event (i.e., out of the country, progression of an illness). When choosing an Agent, the principal must ensure they can trust the individual delegated to the position. They will be giving extensive power to the Agent on their behalf.

- **General Power of Attorney** allows an agent to act on behalf of the principal in any matter allowed under state law regarding financial matters. Examples include buying or selling real estate, managing government benefits like social security, signing checks, filing taxes, etc. The POA will expire when the principal becomes incapacitated or incompetent.
- **Special or Limited Power of Attorney** allows an agent to act on behalf of the principal in limited capacity for a specific purpose or a specific amount of time. Limitations will be in writing at the time the POA was created (i.e., principal is out of town for the summer and the limited power authorization is only during the time they are gone).

- **Durable Power of Attorney** allows an agent to act on behalf of the principal in any matter allowed under state law for financial matters, like a general POA, but they can continue to act on behalf of the principal if they become incapacitated. Durable POA can prevent the need for a court appointed guardian or conservator. Durable POA can go into effect immediately or when certain criteria are met (i.e., principal is incapacitated in the hospital). Many states presume a power of attorney is durable unless stated otherwise in the POA documentation. It is important to seek legal counsel when creating your document.
- **Medical or Health Care Power of Attorney** allow an agent to make decisions on the course of health care treatment for the principal. You can name the same agent for all POA's, or you can name a different agent for each POA. For Medical Power of Attorney, you do have the option of naming alternative agents if your primary agent is unavailable, unwilling, or incapacitated to make decisions on your health care. When designating an agent, make sure they are clear on your wishes if you become incapacitated. Medical POA's are considered an Advanced Treatment Directive.

Representative Payee is a friend, relative or agency who manages an individual's benefit income received from the Social Security program. Individuals who receive Social Security Benefits are known as a beneficiary. If a beneficiary is unable to manage their finances or chooses to relinquish responsibility, the Social Security Administration can designate a representative payee to receive the benefits on behalf of the beneficiary. Representative payees are responsible for taking care of the beneficiary's current needs, future needs, and to save any money not spent taking care of those needs. A guardian is the first option for a representative payee, but if no guardian is available or wishes to be the payee, the Social Security Administration will choose a public or non-profit payee service. Payee organizations can charge a monthly fee for their payee services. If the guardian would like to be the representative payee; they will need to fill out a list of forms through the Social Security Administration to become appointed as a payee. For a list of payee services see the Finance section of this guide.

Special Needs Trust or Supplemental Needs Trust (SNT) is an account designed to provide supplemental funds for living expenses that cannot be covered by any public benefit programs for an individual diagnosed with a physical, mental, or intellectual disability defined by the Social Security Act. The individual does not need to receive Social Security Benefits to have an account. Having an SNT allows an individual to have a financial account with a balance that can go beyond set limits on certain public benefit programs (i.e., Section 8, Medicaid, SSI, etc.). Having funds in an SNT will not cause the individual to be disqualified from those needed benefits.

An individual with an SNT will not have direct access to their funds, but will have a designated trustee (i.e., family member, friend, 3rd party company). A trustee is decided at the time of the trust being opened. The trustee oversees the SNT and will be tasked with disbursing assets for the individual as needed and helping them with financial management of the account. For an individual to have access to the money, they will request money from the trust. The trustee is responsible for the amount of money in the trust, how the funds are being spent, ensure the money spent does not impact benefits, and to keep updated on the changes to SNT rules and regulations at the state and federal levels.

There are three types of Special Needs Trust:

- **First-Party Special Needs Trust or Self-Settled or d4A** is funded by the individual diagnosed with the disability. These funds could come from a lump sum settlement from a lawsuit or from an inheritance that was paid directly to the individual. This SNT can only be established by select individuals (i.e., the individual diagnosed with the disability, their parent, grandparent, legal guardian, or the court). There are several items to consider before choosing this SNT. If funds are still in the trust at the time of the account owner's death, the remaining balance must be paid to Medicaid, if the individual received any Medicaid funding during their lifetime. The trust cannot be changed once established. The trust must be established and funded before the account holder turns 65.
- **Third-Party Special Needs Trust** is funded by someone else's money and not the individual diagnosed with the disability (i.e., inheritance, gift from family member or friend). There are no age restrictions for this SNT and it can be established by anyone for the individual. At any time, the SNT can be revoked (i.e., funds are no longer needed, the funder needs access to the funds their child no longer needs). If funds are still in the trust at the time of the account owner's death, Medicaid does not have a payback provision like a First-Party Special Needs Trust. This SNT can be established and funded at the time of someone's death (i.e., at the time of a parent's death) or can be established and funded while all family members are living. If funded at the time of living, you allow anyone to put funds into the account or if other family members pass (i.e., grandparents), they can leave an inheritance into the trust for the individual.
- **Pooled Special Needs Trust or Medical Assistance Pooled Trust or d4C** is funded by the individual diagnosed with the disability money or by someone else's money (i.e., lump sum settlement, inheritance, gifts, etc.). Pooled SNT defers from other SNT's with the trustee being designated as a non-profit organization. Like other trustees, the

non-profit is responsible for following all federal and state rules and approves the use of funds from the account. There is usually a fee associated with having a Pooled SNT but can cost less than setting up an individual trust. Pooled SNT cannot be changed once established and the State of Iowa is the residual beneficiary of the trust.

Things that can be purchased using SNT fund are items considered as wants for the individual and should benefit their daily life:

- Burial – burial expenses, funeral arrangements
- Dental Services
- Electronics – cable, computer, internet, phone, tablet, television
- Entertainment – tickets to a concert or movie
- Hobbies – crafts, books, art supplies
- Household & Personal Care – clothing, furnishings, furniture, haircuts
- Medical Care – not covered by Medicaid or Medicare
- Pet – new fish
- School – books, tuition
- Trips – Family vacation, weekend trip with friends
- Vehicle – gas, insurance, maintenance, purchase

Things that cannot be purchased from the SNT generally fall under food or housing. Talk with your trustee to decide if the need to use the trust outweighs the loss of some SSI benefits:

- Association Dues – Homeowner or Condo Associations
- Groceries, food, or meals out at a restaurant
- Items for Others – donations or gifts
- Mortgage or Rent
- Property taxes
- Utilities – electricity, gas, water

To learn more about Special Needs Trusts and Pooled Trusts visit <https://www.ablenrc.org/understanding-able-accounts-special-needs-trusts-and-pooled-trusts>

Supported Decision Making is a plan to meet with a team of trusted people to assist an individual when making decisions. The individual has the final decision but has a team of people to help assist them in the process. Team members can include family, friends, medical providers, case managers, etc. When creating the plan, an individual can decide what areas of their life they may need extra help on when having to make decisions (i.e., housing, finance, etc.) and who they want to help talk through the decisions with (i.e., parents, aunt, sister, friend, etc.). The team members will talk through the pros and cons of decisions (i.e., voting in the next election, what college to attend, starting a relationship with someone, etc.).

Wills are a legal document expressing the preferences of an individual regarding the distribution of their assets after death. Items of distribution include belongings, money, and property. Anyone over the age of 18 should have a last will in place and updated regularly to ensure their wishes are met. Seek legal counsel when creating or updating your will.